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WRONGFUL LIFE?

The strange case of Nicholas Perruche

The law tells stories. So argues Catholic legal scholar Mary Ann Glendon in her short but fascinating book, *Abortion and Divorce in Western Law*. Glendon draws on anthropologist Clifford Geertz's claim that law is a "culture system"—it "tells stories about the culture that helped to shape it and which in turn it shapes: stories about who we are, where we came from, and where we are going." Law's stories, Geertz and Glendon argue, cannot but constitute who we are. Its language and concepts become part of our ordinary language and influence how we perceive reality.

At times, though, a law attempts to advance a story that seems radically out of step with what we understand to be true, with who we believe we are or who we wish to become. Such cases illustrate law's constitutive power. A poignant example that has been wending its way through the French courts is the case of eighteen-year-old Nicholas Perruche, who recently won a claim for "wrongful life."

Nicholas was born in January 1983. Four weeks into his gestation, his four-year-old sister contracted German measles. His mother, aware that German measles can cause severe congenital handicaps, told her physician that if she tested positive for the disease she wanted an abortion rather than risk giving birth to a severely handicapped child. Mrs. Perruche underwent two blood tests, two weeks apart. Laboratory error gave contradictory results. Instead of pursuing the matter further, her physician advised her that she could "safely continue her pregnancy."

Nicholas's profound handicaps became evident soon after his birth. He cannot hear, cannot speak, and is mostly blind. His heart is weak. He moves only when carried or put into a wheelchair. Mrs. Perruche suffered a mental breakdown when Nicholas was two, requiring psychiatric care. His parents subsequently divorced.

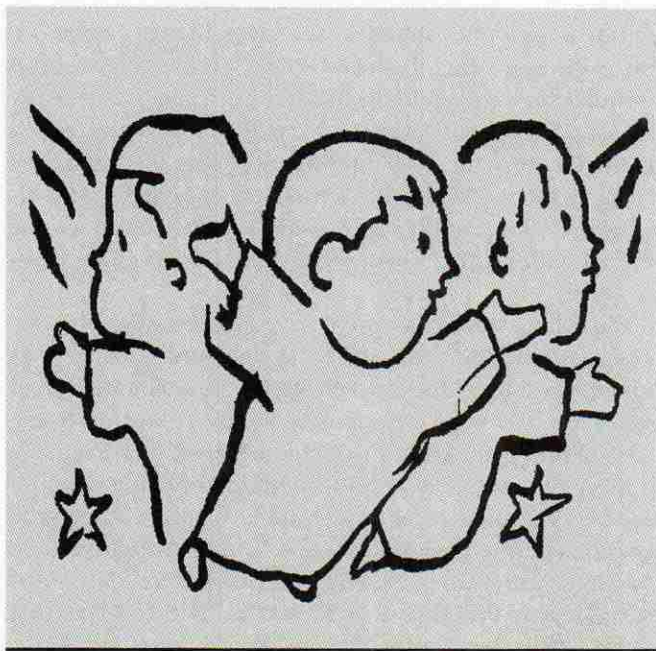
Today, Nicholas lives in a government institution and spends alternate weekends with his mother and father. But his parents were concerned that after the age of twenty, he would probably have to leave the institution and require permanent private care. The family first went to court in 1988. Arguing that the error of the laboratory and the physician had brought suffering to the family, the Perruches were awarded approximately \$13,000 in damages.

Had the case ended here, it would have been novel enough, presenting the first appearance in French jurisprudence of a concept indigenous to the U.S. legal landscape, namely, "wrongful birth." "Wrongful birth" suits claim that the negligence of health-care providers (for example, botching sterilizations, failing to inform about a prenatal test, or

misdiagnosing a fetus's handicap) prevent the mother from exercising her right of autonomy and thus to abortion. Wrongful birth claims have been advanced when the "birth" resulted in children both with and without disabilities.

Wrongful birth cases differ from traditional malpractice suits in two ways. Traditional malpractice suits (which in these situations might be brought under "wrongful conception" or "wrongful pregnancy") describe the "damage" as a medical or physical harm to the mother. This would not include the existence of a child one would rather not have. Consequently, malpractice compensation is generally limited to recovery for damages associated with pregnancy itself (loss of wages, costs of pregnancy and delivery, etc.) as well as emotional duress. In wrongful birth cases, the damage lies not with the pregnancy itself—Mrs. Perruche, for example, was not opposed to being pregnant nor to giving birth to a second child. The damage lies rather in the burden that this particular child imposes on the life of the parents and family. Wrongful birth suits seek additional compensation for wages lost because of the care required by special-needs children, and for the medical, educational, and emotional costs associated with the child's disability. Typically, these costs are only compensated until the child reaches the age of majority.

But Nicholas's case is not solely one of wrongful birth. In addition to arguing for damages on their own behalf, the Perruches sued the laboratory and the physician on Nicholas's behalf, arguing that Nicholas himself had been harmed by their errors. On four occasions, Nicholas was awarded damages, but each time the verdicts were reversed on appeal. Last July, the Cour de Cassation, the French equivalent of the Supreme Court, upheld a 1991 lower court ruling that awarded Nicholas damages. The court argued that because the errors of the physician and the laboratory "had prevented Mrs. Perruche from exercising her choice to end the preg-



CHARLOT

Blue Wagon

Left out in the rain far too long,
For too many seasons, now rust
Has crept along its stenciled sides,
Turned its white wheels brown and black,
Left its steering rudder scoured
Down to the metal of its base.
It works still, complaining to the touch
As over grass and clumps of earth
It follows feet and frantic dogs
Into the light of evening.

Things are like this all the time—
Thoughts too. They are molded out of
Baseness and into it slyly turn,
Neither decline nor fall, only
Windings this way and that
As if seeking, not surety, not truth,
But a flume of seasoned wear.

Harold Bordwell

nancy in order to avoid the birth of a handicapped child, the latter can ask for compensation for damages resulting from his handicap." The Perruches were awarded about \$68,000 with a further \$250,000 to cover the cost of Nicholas's lifetime care.

With this decision, the French courts imported the additional U.S. concept of "wrongful life." "Wrongful life" suits do not claim that the physician's negligence caused the impairment (as would a malpractice case). Rather, "wrongful life" suits argue that the health-care provider's error is responsible for the plaintiff having been born and consequently experiencing the suffering and incurring the expense caused by the impairment. The impairment causes the harm. The "wrong" is attributed to the birth itself, implying that in his being born the plaintiff's rights were violated. Nicholas, the wrongful life claim implies, had a right to be terminated before birth.

The ruling caused an uproar in France. Persons with disabilities criticized the decision as demeaning of them as human persons. Ethicists criticized it for encouraging eugenics. As 2001 wore on, opposition to the ruling increased, culminating in a strike of sorts by outraged physicians. In January the twenty-four-hundred-strong National Syndicate of Gynecologists and Obstetricians began refusing to perform routine ultrasound scans. The doctors argued on pragmatic grounds, citing fear of lawsuits should disabled babies be born. But their action resonated with a deeper sensibility across the country. Shortly after the strike began, the

French National Assembly called an emergency session and passed legislation forbidding plaintiffs to seek damages simply for having been born. The bill passed by an overwhelming margin.

The first successful "wrongful life" case in the United States was the 1984 decision of the New Jersey Supreme Court in the case of Peter Procanick (whose mother, like Josette Perruche, contracted German measles in her first trimester). But Procanick saw no overwhelming congressional response. U.S. obstetricians and gynecologists certainly did not go on strike. Ethicists seem to have barely batted an eye. Why? And why was the French response so different? How might we account for these differences? One answer, I would suggest, lies in our national stories, as captured in our respective abortion laws.

What is the story that French abortion law tells? Two features seem very similar to U.S. statutes. In France, abortion is available up to the tenth week of pregnancy to any woman "whose condition places her in distress." "Distress" is simply defined by the woman. After ten weeks, only "therapeutic" abortions are permitted, for situations that pose a threat to the woman's health or when "there is a strong possibility that the unborn child is suffering from a particularly serious disease or condition considered incurable at the time of diagnosis."

Three features of France's abortion law, however, provide clear points of departure from the U.S. situation. First, the language of the statute clearly *names* the fundamental issue as one involving human life. Its first sentence reads: "The law guarantees the respect of every human being from the commencement of life. There shall be no derogation from this principle except in cases of necessity." Second, the statute specifically outlines ways in which the state is to take an active part in promoting respect for life: "The teaching of this principle and its consequences, the provision of information on the problems of life and of national and international demography, education toward responsibility, the acceptance of the child in society, and family-oriented policy are national obligations." Toward these ends, the state provides substantial financial support for women and their children. Finally, the statute mandates several procedures—including a counseling session—designed to make the woman aware of, and able to choose, alternatives to abortion.

As such, the story told by French abortion law seeks to balance, as Glendon notes, compassion for pregnant women with concern for fetal life and expresses the commitment of society as a whole to minimize occasions when a tragic choice has to be made between the two. Nonetheless, the overarching theme of the story is that of "respect for every human being from the moment of commencement," a respect that the state is obliged to foster. That the French believe this to be the state's obligation makes sense in a country twice ravaged within recent memory by war. (This link is seen even more clearly in German abortion laws, where the courts expressly root their commitment to the protection of unborn human life in the experiences of World War II.)

The claim that Nicholas was *harm*ed by not being aborted tells a very different story. It suggests that "respect" entails destruction rather than nurture. (This claim is currently advanced in the United States within the human embryonic stem-cell debate.) It does not suggest that abortion is a tragic action of individual conscience that the state will allow as a compromise while working against it. Rather, it suggests that at times the destruction of human life is a "right," a good to be pursued. Ironically, in a dark inversion of the claim to a right to life, the right to be terminated prior to birth becomes the only right fetuses with disabilities possess. By issuing this decision, France's highest court suggested that the state ought to support the destruction of specific human beings.

The rejection of the court's ruling by the French populace, medical professionals, and legislators suggests that this is not their story. It does not describe who they understand themselves to be. And it is not who they want to become.

In the United States, of course, *Roe v. Wade* and subsequent legislation tell a very different story. U.S. laws start out not from respect for every human being but rather from the fundamental conflict between a woman's individual liberty or privacy and a "nonperson." Moreover, U.S. laws prohibit states from instituting the kinds of policies that are required in France in order to make women aware of and able to choose alternatives to abortion. Such policies have been repeatedly interpreted as creating an "undue burden." Of course, given the dismal public support for maternity and child rearing in the United States, real alternatives do not exist for many women. Thus, the U.S. legal narrative tells a story in which the state is limited in its obligation to protect human life and has little responsibility to actively nurture and foster the lives of those within its purview. In this context, "wrongful life" is the logical extension of the story told by *Roe*.

But the question remains: What about Nicholas? The French were unwilling to allow him to be described in terms that rendered his life not worth living. They refused to cast him as a person whose burdens outweigh his inherent value and negate the goodness of his existence. They did not wish the concepts associated with "wrongful life" to enter into the way they see and will see persons with disabilities.

What resources might we in the United States have to counter the description of persons with disabilities offered by "wrongful life" cases? The picture is mixed. The law itself might provide one antidote. Currently only three states recognize wrongful life suits—New Jersey, California, and Washington—while twenty-three state appellate courts have refused them. This, coupled with the constitutive power of the Americans with Disabilities Act—contested though it may be—challenges the normative claims of "wrongful life" suits vis-à-vis persons with disabilities.

But this very account of our legal situation reveals that the status of persons with disabilities in the United States remains deeply ambiguous. Those who wish to forge a different reality for persons with disabilities will need to turn



"Since you ask, I had you, Samantha, because the birthrate was falling; and you, David, as revenge on society; and you, Mark, as a bid for lost youth; and you, Jason, were a mistake."

HARPER/©PUNCH/ROTHCO

to other stories and practices. I will end by offering just one powerful alternative practice that emerges, coincidentally, from France: the communities of L'Arche.

Founded by Jean Vanier in 1964 and subsequently exported to twenty-four countries including the United States, L'Arche works to create communities of friendship between volunteers and persons with disabilities—disabilities even as profound as Nicholas's. L'Arche intentionally embodies an alternative narrative of who persons with disabilities are and puts that narrative into practice. Against the belief that persons like Nicholas are so profoundly damaged that the good of their existence is negated, L'Arche aims to help them gain a deeper sense of their own worth, as persons worthy of love and friendship, whose value and beauty lie hidden in their weakness. It is a practice premised on a different story—not one of privacy and "nonpersons." It is based on a belief in the reality of the Trinitarian God, a community of persons, in whose image and likeness all of us—visibly handicapped or not—are made. By seeking to live this reality, L'Arche makes its claims "come true" even for persons with profound handicaps and provides a real alternative to the story embodied only in the technologies of prenatal surveillance. In so doing, it not only challenges us to see persons with disabilities differently, it challenges us to understand ourselves, and so to live, differently.

L'Arche and its work, of course, does not deny the tragedy of Nicholas's condition, the loss of who he could have been, and the anguish of his family. It does not deny the pain experienced by those with disabilities, but locates their pain primarily in society's rejection of them as persons. "Wrongful life" claims embody this rejection profoundly. By making manifest the dignity of persons with disabilities, L'Arche challenges the belief that tragedy, loss, and anguish are the only words needed to describe Nicholas's life and that Nicholas's very existence is a wrong above all to himself. □

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